

Episode #16: Grief & Emotions While Caring with Karin Murphy, LPC, CT, GC-C

- 1:46 What is anticipatory grief
- 2:10 Lots of layers of secondary losses after initial diagnosis
- 2:25 Dementia loss of person we knew
- 2:33 As caregiver loss of freedom, identity, my free time
- 2:53 The losses we're seeing and feeling everyday
- 3:11 It's unexpected unpredictable it's on your shoulders
- 3:22 Constantly grieving small ways bigger ways
- 3:30 We might think the feelings are clinical depression
- 3:50 How do you recognize the signs of grief vs depression?
- 4:02 Depressed might not be able to get out of bed
- 4:18 How are you able to function - are you able to do your everyday life? Then it's grief if not it might be depression

- 4:37 It's a nuance diagnosis (depression or grief)
- 4:55 How could you not feel grief?
- 5:05 Grieving for loved one and your own life
- 5:20 Grief is pervasive
- 5:30 Changes dynamic of relationships
- 6:15 Having a normal reaction to something that is very very difficult
- 6:25 Caregivers feel like I must be doing this wrong because I'm feeling this way

- 6:35 This is a normal reaction - being tasked with something difficult
- 6:40 How can we help to reframe that?
- 7:20 Has to be an intentional, conscious practice to allow those feelings to come up or that's where it gets dangerous

- 7:35 Very important to allow yourself the space to allow those feelings
- 7:45 For instance, Daughterhood Circles - Seeking out support from people who understand it and connect with others

- 8:04 Some people need alone time
- 8:10 Journaling, creative outlets, dance, yoga, some way of allowing yourself to feel everything in order to not feel so weighed down

- 8:50 Making the space allows you the opportunity to process what is happening and will allow you to feel a little bit more in control

9:00 At the end of the day do you take 10 minutes and say I'm going to process what happened today?

9:08 It has to be something intentional but doesn't have to be formal

9:23 Put both feet on the floor a literal and figurative grounding and close your eyes and think what went well today, what do I wish I could have done differently today, but also an affirmation to yourself of this is what I did today

9:41 It makes a transition

9:53 Processing and feeling is just checking in with yourself

10:02 Deep breathing techniques can help

10:11 If you can take your shoes off when you put your feet on the floor

10:16 It keeps you in the here and now it keeps you from going into the troubles for tomorrow and reviewing what has happened, you're just there

10:25 It can be helpful just to take it back to that very basic place

10:55 Acknowledge what you're doing is hard

11:23 Afraid to say it's hard because afraid of judgement

11:42 People just need empathy need the ability for someone to listen to them without trying to fix it or telling what you need to do differently

12:04 Comparison and judgement is poison

12:13 You don't need a platitude in a difficult moment

12:22 You need to feel that you've been heard as a human being

12:43 Judgement is a big part of it even when we are thinking about our feelings

13:06 It's not the death of a child that pulls apart a marriage it's the judgement of one another

13:24 It not only invalidates our experience it doesn't help us to feel like people understand what we're trying to say and there's nothing that can be fixed

13:34 It's how can I support you and help you because these are big big emotions

13:53 Being forced in thinking who am I without them

14:13 It's messy it's not what I wanted, this is not what I started off with but this is what I have and what I'm working with right now

14:50 Decisions that caregivers have to make everyday add to the guilt

15:18 And you feel judged on top of that after trying to make the best decision

15:29 You most likely made the best decision at that time for your loved one and you

15:43 It's good enough

15:55 Is it healthy guilt? Unhealthy guilt? How much is shame?

16:06 Hard to sift through all of that while caregiving

16:15 You're going to get triggered

16:25 Does that apply to my situation?

16:32 What they are saying says more about them than about you - talking about their fear and their sense of control

16:43 As a way of coping with something that feels difficult and scary and "oh my God I hope I never have to deal with that"

16:54 It makes them comfortable while it makes you uncomfortable

17:00 Consider the source

17:05 Even if it comes well intentioned from someone that we know and love very much

17:12 Remind yourself that that is them this is me

17:14 Being confident in the choices and the decisions that are being made

17:19 you're in the position that you are because of the relationship with your loved one

17:23 Maybe that does work for somebody else doesn't mean it has to work for you

17:28 Part of it is having confidence for your own gut feeling

17:32 Maybe don't seek support from that person

17:39 Carefully choose who you confide in - Support groups, community

17:51 Going to see a counselor - having that safe space

18:02 Half of it is awareness

18:16 We have to recognize it's not true it's not real it's not accurate

18:32 Visualize a balloon in your hand and seeing your hand open and watching that balloon go

18:50 If you don't give it permission it can't hurt you

19:00 Self compassion

19:04 We would never dream of talking to our children, our best friend other family members why is it okay to be so mean and hurtful to ourselves

19:17 We are at a place we never thought we would be so we're still learning

19:21 Talk to yourself like you would to your best friend and be open to that

19:32 No manual, no handbook and what works for one person isn't necessarily going to work for you and your situation

20:00 It might not be what your used to but it's okay

20:08 It's learning to trust your inner voice

20:14 We have everything we need inside of us, it's just learning to tap into that to listen to trust and to be able to make decisions based on that

20:44 Big emotions and heaviness and sometimes we aren't really taught how to honestly talk about how we're feeling

20:59 Because there's all sorts of judgement and labels on what is good and what is bad and if I was a good daughter I wouldn't feel this way

21:13 More about being curious - why am I feeling anxious? Why is my chest tightening

21:30 Awareness of where you're feeling it in your body

21:35 Noticing why am I over eating, not eating sleeping too much not sleeping

21:44 Being curious instead of assigning good or bad

21:47 Then we're just curious

21:53 Our emotions are just a different way of taking in information

21:56 Think about things feel them and then it helps us to make the best decision for ourselves

22:04 When I'm eating my feelings what do I do?

22:26 Put both feet on the ground take a deep breath and check in with yourself

22:34 What am I feeling right now where am I noticing that in my body

22:40 What happened right before here or earlier today that I'm really struggling with that this is my way of soothing myself right now

22:55 Am I going to have the strength to do this at the end of the day -

22:57 That's where the other components can come into play - going for a walk support group, journaling, doing some yoga healthy forms of coping

23:21 Having a plan - next time I find myself here I'll call a friend who is not going to judge me

23:38 We understand intellectually what needs to be done emotionally it's a lot harder

24:45 If we knew the answer there wouldn't be so many things to help avoid

24:20 Think of time together as she's holding a giant platter, talking about them and seeing them in front of you makes it feel lighter when you pick it back up and take it back home with you

24:45 Reframing it makes it feel more manageable

24:57 If you don't have a trusted someone find a therapist to help reframe situations

25:20 Therapy is a safe space to explore

25:34 Beauty of a support group is you don't have to explain

25:52 We just need someone to be there

26:00 Alzheimer's association - aging [care.com](https://www.care.com) message boards if you can't get somewhere

26:40 As caregivers sometimes we feel like we have to have all the answers - feels like a shortcoming if we don't know

26:52 Somehow by not knowing we're supposed to be quiet until we do know the answer and that's a struggle

27:00 Feel like you have to know everything

27:27 You are the one who is deciding

27:50 Decision for hospice

27:55 Your loved one and the disease process happens all on it's own - you aren't making the choice for end of life

28:05 When you're noticing the changes and realizing the changes you're just acknowledging what's happening

28:16 It's facing the fear, facing reality

28:19 You did not make that happen - You are choosing to find support to help you at that time

28:30 Not being able to face the reality, as difficult as it is, is what keeps people from getting hospice support earlier than later

28:55 Hospice can be beautiful for the patient and for the family's support

29:02 As a caregiver you are not responsible for what happened

29:07 You are doing a loving act by making that phone call

29:20 Hospice is usually reserved for person six months or less to live

29:45 Palliative care is a different conversation

29:57 If we can remember it's not like we're sending our loved one off to something

30:00 We are being guided by medical professionals outside of your family unit who are able to look at situation objectively

30:15 Social worker, chaplain to help with issues, bereavement coordinator

30:33 It's one more decision

31:00 Those choices add to anticipatory grief

31:07 As disease progresses those decisions weigh more

31:16 Anticipatory grief of what's to come and so much is unknown

31:22 Part of being a caregiver is that sense of responsibility

31:28 If I had only done this maybe we wouldn't be here - If I had only done this at that point

31:30 Second guessing and judgment on ourselves

31:41 Instead of feeling like I'm making the best decisions I can everyday and that is enough

31:51 Put sticky notes around that say That Is Enough

32:15 Strategy that we can work into our lives

32:28 Trial and error what works for one person may not work for the other

32:40 Get up an hour before loved one to give themselves time to have coffee or read a newspaper, whatever it is that feels life giving that you're being fed

33:05 Not morning person maybe carve out time at the end of the day that's just for you

33:14 Coming up with a plan, maybe having a checklist

33:19 If I'm having a bad day what can I refer back to

33:26 Having that space whatever it looks like just to have an opportunity what am I feeling? What do I need help with is there anything I can give myself some Grace on

33:38 Realizing that sometimes it's just recalibrating your expectations for yourself

33:42 You're not out to change the world, you're there for your loved one and what do I need to do today

33:47 More time for yourself at any time during your schedule sometimes even if you can just escape to the bathroom in the middle of the day and shut the door to breath a little bit

33:58 Check in with yourself what's going on here

34:05 Gives us a more proactive not a reactive response to what's going on

34:10 When we can come from a place of rest when you feel like you are full is when you can give

34:18 When you feel like you are running on empty it's very hard to be patient it's very hard to give what you don't have

34:28 "How am I supposed to?"

34:40 When we get on an airplane- Put your oxygen mask on first before you can help anyone else

34:50 it's not selfish to give yourself the time you need

34:52 Get a family member to come spell you so you can get some time away

34:58 It is harder in Covid but need to be more creative

35:04 Finding ways to give to yourself whether it be morning evening or middle of the day or multiple times

35:13 It's not selfish or a luxury, it's a necessity

35:18 You have to have that replenishment in order to be there for your loved one

35:27 Running ourselves into the ground doesn't help anybody, no one benefits from that

35:36 It may be how you've operated in the past but I feel like being a caregiver is sort of like a way for you to challenge those thoughts and beliefs and expectations because it has to be different moving forward

35:53 We all have a preference for how we would choose but unfortunately that's not always available to us

36:00 Acknowledging that things maybe are not happening the way we would like, when I say accept that I'm not saying that means you have to like it it's just how it is right now

36:12 This is what I have to work with

36:14 Finding a way to be kind to yourself in the process and doing it in bite size pieces because that's really important

36:22 Because with the grief, the anticipatory grief it's easy to project into the future and we don't know, we can't make predictions as to what's going to happen

36:34 Really trying to stay in the day, day by day in the moment in the day and stay grounded

36:46 Grief does not have to be just about grieving someone who has died - there are plenty of non-death losses that we grieve in little ways and in big ways each and every day

37:04 Because it is associated with something not great We don't want to spend time thinking about it or feeling it but it is part of making us a whole human being to be able to find ways to talk about it and feel it and to know that it's okay, we're going to pass through that as well

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<https://www.kaleidoscopecounseling.net/>

SUPPORT GROUPS WE MENTIONED

<https://www.daughterhood.org/circles-2/>

<https://www.alz.org/>

<https://www.agingcare.com/>